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The Reliability of Spina Bifida Videos on YouTube

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Abstract

Objective: Spina Bifida occurs as a result of incomplete closure of the neural tube between the 28th and 30th days of the embryological period. It is usually detected at the intrauterine time. Access to information has become easier with the development of technology in recent years. The easiest example of this is that patients apply to the internet to get information about their diagnoses. We aimed to examine the medical video quality on YouTube by doing a study on Spina Bifida.

Methods: The first 50 videos were determined by typing Spina Bifida in the YouTube search engine. These videos were evaluated by 2 researchers using the DISCERN scoring system. Videos were analyzed according to their source, number of views, and number of likes and dislikes.

Results: The average length of the videos was 11.2 minutes, and the average number of views per day was 28.24. The average DISCERN score was 1.78. Overall video quality was found to be "poor." When the videos are analyzed according to their sources, the publications made by the hospital/doctor constitute 44% of all the publications. Although the videos published by the hospital/doctor are of the highest quality with an average of 1.9 DISCERN, they were determined as poor quality according to the DISCERN criteria. Patient sharing was determined as the most inadequate video with a DISCERN average of 1.36.

Conclusion: YouTube is not a reliable platform for getting information. The analyzed Spina Bifida videos also support this. YouTube videos should not be recommended as a medical information retrieval tool.

Keywords: Information, Spina Bifida, YouTube

Spina Bifida is a neurulation defect caused by the incomplete closure of the neural tube during the 3rd and 4th weeks of the embryological period.[1] Usually a cleft or a gap occurs in the spine that exposes the spinal cord to damage. There are 2 kinds of Spina Bifida: open spinal dysraphism and closed spinal dysraphism. Open spinal dysraphism refers to the condition in which the meninges and/or nervous tissue are exposed to the external environment. Closed spinal dysraphism is the mildest form and it refers to the condition in which the meninges and the nervous tissue are covered by skin.[2]

Spina Bifida is one of the most common central nervous system congenital anomalies of the neonatal period.[3] The incidence in Turkey is 3-5 per 1000 births.[4] Worldwide, each year approximately 150 000 babies are born with Spina Bifida.[1] In the etiology of Spina Bifida, maternal folic acid deficiency, chromosomal anomalies, genetic disorders, geographical and ethnic differences, diabetes, and anticonvulsant drug use can be seen.[5-7]

There is a lot of online information about Spina Bifida which causes sensory and motor disturbances, orthopedic disturbances, bladder and bowel dysfunction, and occasionally cognitive impairment. Parents in the newborn period and later patients turn to YouTube to gather more information about their diseases. YouTube is one of the biggest internet platforms with its more than 1 billion users,[8] and the second most visited website after Google search engine.[9] Since YouTube is used as an information source, it is necessary to take measures in video quality. In several studies, the quality of health-related videos on YouTube has been found to be poor.[8-10]

This study is the first to evaluate YouTube videos with the keyword "Spina Bifida." Our aim is to evaluate the quality and reliability of "Spina Bifida" videos on YouTube by using DISCERN scoring system (Table 1).

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Materials and Methods

Search strategy and data extraction

An online search was performed by entering the keyword "Spina Bifida" into the YouTube search engine. The search results were sorted by "Relevance." The search was carried out by A.Ö. on May 5, 2021, and the first 50 results were recorded. No filters were used in the search. For each video, criteria such as video length, the number of daily views, the total number of views, the number of likes and dislikes, the number of comments, and the video source were determined. Videos were watched and scored independently by 2 healthcare professional researchers (A.Ö.—researcher 1 and O.B.—researcher 2) using the DISCERN scoring system and a database was created.

Scoring system

DISCERN is a questionnaire that evaluates the quality and reliability of a publication with 15 questions that score from 1 to 5.[10] According to DISCERN scoring system, videos with a score of 4 or more have "good" quality and are useful and are appropriate sources of information about treatment options. Videos with a score of 3 have a "moderate" quality and are useful sources of information about treatment options; however, they definitely

Table 1. DISCERN Scoring Criteria[8]

Question Number	What Is Investigated?	No Partially			Yes	
Section 1	Is the publication reliable?					
1	Are the aims clear?	1	2	3	4	5
2	Does it achieve its aims?	1	2	3	4	5
3	Is it relevant?	1	2	3	4	5
4	Is it clear what sources of information were used to compile the publication (other than the author or producer)?	1	2	3	4	5
5	Is it clear when the information used or reported in the publication was produced?	1	2	3	4	5
6	Is it balanced and unbiased?	1	2	3	4	5
7	Does it provide details of additional sources of support and information?	1	2	3	4	5
8	Does it refer to areas of uncertainty?	1	2	3	4	5
Section 2	How good is the quality of information regarding treatment choices?	1	2	3	4	5
9	Does it describe how each treatment works?	1	2	3	4	5
10	Does it describe the benefits of each treatment?	1	2	3	4	5
11	Does it describe the risks of each treatment?	1	2	3	4	5
12	Does it describe what would happen if no treatment is used?	1	2	3	4	5
13	Does it describe how the treatment choices affect overall quality of life?	1	2	3	4	5
14	Is it clear that there may be more than 1 possible treatment choice?	1	2	3	4	5
15	Does it provide support for shared decision making?	1	2	3	4	5
Section 3	Overall rating of the publication	1	2	3	4	5
16	Based on the answers to all of these questions, rate the overall quality of the publication as a source of information about treatment choices	1, 2, 3 Low Moderate			4, 5 High	

need additional support. Videos with a score of 3 or less have "poor" quality and they are not appropriate information sources about treatment options.[10]

Classification of video sources

Videos were classified into 5 categories according to their source as hospital/doctor sharings, educational sharings, patient sharings, health information websites, TV programs/news.

Statistical analysis

Mean, median, standard deviation, and minimum and maximum variance were calculated for the data. Using the Pearson correlation test, it was checked whether the evaluation scores with normal distribution of each researcher were different. Since the variance of the evaluation scores of the video sources calculated with one-way analysis of variance (ANOVA) were homogenous, the Bonferroni test was used as a post hoc test to determine which test was different. The videos were examined in terms of content and mentioned topics were compared according to DISCERN average values using a single sample *t*-test.

Results

When the videos are examined, the average video length is 11.2 minutes (00:26-59:59 minutes), the average number of daily views is 28.24 (min-max: 0.15-333.19), the average total number of views is 47 068 (min-max: 111-745 015), the average number of likes is 213.58 (min-max: 0-4800), the average number of dislikes is 8.8 (min-max: 0-90), and the average number of comments is 14.2 (min-max: 0-185) (Table 2).

The scores given by each researcher were analyzed separately using DISCERN scoring system. According to the scoring system, the mean score given by researcher 1 is 1.79 ± 0.37 (min-max: 1.10-2.46), and the mean score given by researcher 2 is 1.77 ± 0.36 (min-max: 1.13-2.46) (Table 3). According to DISCERN scoring system, the variances of the total scores for YouTube videos given by each researcher are homogenous (Levene test). The scores given by the researchers according to the scoring systems showed a high level of positive correlation. (Pearson correlation test: $P < .05$, $r = 0.882$).

When the videos are analyzed according to their source, hospital/doctor sharings constitute 44%, educational sharings 12%, patient sharings 10%, health information websites 22%, and TV programs/news 12% (Table 4). Mean DISCERN scores were compared using one-way ANOVA test. A statistically significant difference between sources was found ($P < .05$). In order to make a comparison between the sources, the Bonferroni test was used as a post hoc test. According to the results, a significant difference was found between hospital/doctor sharings and patient sharings ($P < .05$).

According to both researchers, the reliability ranking of the videos based on DISCERN scoring system is as follows: hospital/

Table 2. General Information About the Videos

	Video Length (Minutes)	Number of Daily Views	Total Number of Views	Number of Likes	Number of Dislikes	Number of Comments
N	50	50	50	50	50	50
Mean	672.83	28.24	47068.08	213.58	8.8	14.20
Median	207	4.65	2666.50	19.50	1.0	3.0
Standard Deviation	1026	66.84	128032.75	719.19	19.74	31.53
Minimum	26	0.153	111	0	0	0
Maximum	3599	333.19	745015	4800	90	185

Table 3. Total and Individual Scores Given by Each Researcher According to the DISCERN Scoring System

				95% CI for Mean			
	Mean	Standard Deviation	Standard Error	Lower Limit	Upper Limit	Min	Max
Researcher 1	1.79	0.37	0.05	1.68	1.89	1.1	2.46
Researcher 2	1.77	0.36	0.05	1.67	1.87	1.13	2.46
Total	1.78	0.36	0.05	1.68	1.88	1.15	2.43

doctors sharings (mean: 1.90), educational sharings (mean: 1.80), health information websites (mean: 1.79), TV programs/news (mean: 1.64), patient sharings (mean: 1.36). When the hospital/doctor sharings were examined separately, it was seen that most of the videos shared were prepared by neurosurgeons and physiotherapists who were experts within their areas. Forty percent of the evaluated videos mention the mechanism behind the disease, 54% the symptoms of the disease, 10% the risks of the surgery, 58% the treatment methods, 66% prognosis of the disease, 14% the risks without the surgery, and 26% the diagnosis methods. Within 64% of the videos, doctors are giving information about the condition, and within 20%, animations are being used as supplementary material. We examined how these criteria affected the quality of the videos. It was determined that videos with doctors talking, videos containing animations, and videos mentioning diagnosis and mechanisms were significantly different from the general average of videos. (Single sample *t*-test, $P < .05$).

Discussion

Access to information has accelerated very fast in the last 20 years. The biggest reason behind this is thought to be technology.

Table 4. Video sources, Number of Likes, Dislikes, and Comments

Video Source	N	Number of Likes	Number of Dislikes	Number of Comments
Hospital/doctor shares	22	146	10	9
Educational shares	6	115	6	9
Patient shares	5	273	10	30
Health information websites	11	469	9	19
TV programs/news	6	42	6	16

With the rapid progress of technology, we can use mobile phones that are always with us for online access. Parallel to this progress, it has become widespread to search for medical issues in online media. In a study from Canada, it was found that about 70% of people try to gain information online before applying to a hospital.[11,12]

At the top of the video access websites is the open-access YouTube.[13,14] It contains several medical videos such as medical treatment and diagnosis of diseases.[15] Videos on YouTube can be wrong and biased as the website has open access and there is no control over the accuracy of the data. There are some studies evaluating the reliability and accuracy of the videos on YouTube.[9,15,16] However, there is no study that evaluates the reliability and accuracy of videos on YouTube about a congenital problem, "Spina Bifida."

The same methodology with the previous studies on YouTube was used while analyzing the videos on "Spina Bifida."[15,17-19] Many studies have been done on YouTube videos giving information about medical issues. The common result of the studies on YouTube videos about the spinal area such as lumbar microdiscectomy,[8] anterior cervical discectomy and fusion,[10] and scoliosis[19] is that information on YouTube is of low quality.

In a study by Gokcen and Gumussuyu on lumbar disc surgery, DISCERN score was found to be 1.92,[8] which was close to our result. These results show that the video quality is poor not only in our study but also in the analyzes on different areas. In our study, there were no videos that had a DISCERN score above 3. In a study done by ReFaey et al. on glioblastoma, 22% of the videos had a score of more than 3; however, the video quality was found to be poor in general.[9] It is very difficult to reach the right information on YouTube which has a very large data pool. The alternative medical views which have not passed the academic process, incorrect diagnosis and treatment algorithms, and insufficient data on which treatments can be applied in each condition cause information pollution. This pollution causes patients to end up with wrong and undesired results.

In our study, the majority of the YouTube videos reviewed were not shared by health professionals. The percentage of the videos uploaded by health professionals was 44%. Looking at other studies, in Gokcen and Gumussuyu's study, 48% and in Ovende's study, 54% of the videos were shared by health professionals.[8-10] These studies and our study have shown that the number of videos uploaded by nonhealthcare professionals is quite high. It was also concluded that the quality of the videos shared by healthcare professionals is higher.[15] Even though the average DISCERN score of hospital/doctor sharings, educational sharings, and health information sharings did not exceed 3, these sources give higher quality information than the other sources. We concluded that the factors lowering the quality of videos are not mentioning the reference sources while trying to give the main and essential information about the condition, skipping the uncertainties in which academic unity has not been achieved, not explaining the principles of each treatment, and not emphasizing the risks of the treatments. Even the Hospital/doctor shares prepared by experts have a low quality score. These videos, which are prepared without complying with the academic criteria, do not meet the expectation.

In a study done by Pew Research Center, it is shown that 75% of people do not pay any attention to the sources while watching the videos.[20] When the videos are examined according to the number of likes, we can see health information websites and patient sharings have the highest number of likes. Hospital/doctor contents follow these. When the comments are examined, we can see patient sharings have the highest number of comments. The number of comments and the number of likes does not comply with the DISCERN scoring system in which we examined the video quality. Hospital/doctor sharings, which have the highest score in our study, have less likes and comments compared to other contents. Some publications claim this is because the videos shared by health professionals are more difficult to understand.[21] Under the light of the result of these studies, healthcare professionals should use criteria such as DISCERN which measures the video quality and uses simple language while sharing videos.

In our study, Spina Bifida videos were examined by content and the way they were made. The study showed that videos of doctors talking have a higher score. In support of this, there are studies showing that videos of doctors talking have higher quality.[22] The videos of doctors talking and the videos with animations were found to have higher quality, even though they do not have the standards of a good quality video. The presence of healthcare professionals and animations within the videos being produced from now on will increase the information quality of the videos.

The limitation criteria of the videos being examined were determined according to the literature.[19-23] The first 50 results were evaluated by searching the keyword "Spina Bifida." This can be thought of as a limiting factor for the study; however, as it was indicated in the literature,[24] people who are looking for online information generally look at the first results. Also, it should be considered that the results can differ when the search is made at a different time. In order to prevent this, the researchers watched the same videos which were recorded within the same day. Searching in another language while the search language is Turkish can cause different results. This study is a cross-sectional study that examines a limited amount of information from YouTube.

A YouTube video that shares medical information should explain the mechanism of diseases, diagnosis methods, treatment methods, and situations that may occur without treatment, with literature, by healthcare professionals with supplementary animations. Guidelines on how to create online content that were published.[25] It was found that the majority of the videos on YouTube do not follow these guidelines. This study showed that YouTube is not a proper source of information for patients, and physicians should give comprehensible and detailed information to the patients on Spina Bifida.

With the development of technology, sharing information has become quite easy. As a result of this, patients and their relatives turned to online sources for gathering medical information. YouTube is one of the most visited websites for sharing online information. In our study, which evaluated the quality of videos on Spina Bifida, we found that the quality and reliability of these videos are low. It was not known how this situation affects the decision process of patients. However, the up-to-date data shared by healthcare professionals have a huge impact on access to right information. An online platform where medical information is investigated on quality and reliability by experts would be of great step in sharing the right information.

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References

1. Gotha L, Pruthi V, Abbasi N, et al. Fetal spina bifida: what we tell the parents. *Prenat Diagn*. 2020;40(12):1499-1507. [CrossRef]
2. Gupta P, Kumar A, Kumar A, Goel S. Congenital spinal cord anomalies: a pictorial review. *Curr Probl Diagn Radiol*. 2013;42(2):57-66. [CrossRef]
3. Altaş M, Aras M, Altaş Z, Aras Z, Serarslan Y, Yılmaz N. Nöral tüp defektli hastalara retrospektif bakiş. *Mustafa Kemal Univ Tıp Derg*. 2012;3(09):22-28.
4. Tunçbilek E. Türkiye'deki yüksek nöral tüp defekti sıklığı ve önlemek için yapılabilecekler. *Çocuk Sağlığı Hastalıkları Derg*. 2004;47(2):79-84.
5. Mitchell LE, Adzick NS, Melchionne J, Pasquariello PS, Sutton LN, Whitehead AS. Spina bifida. *Lancet*. 2004;364(9448):1885-1895. [CrossRef]
6. De Wals P, Tairou F, Van Allen MI, et al. Spina bifida before and after folic acid fortification in Canada. *Birth Defects Res A Clin Mol Teratol*. 2008;82(9):622-626. [CrossRef]
7. Jentink J, Bakker MK, Nijenhuis CM, Wilffert B, de Jong-van den Berg LT. Does folic acid use decrease the risk for spina bifida after in utero exposure to valproic acid? *Pharmacoepidemiol Drug Saf*. 2010;19(8):803-807. [CrossRef]
8. Gokcen HB, Gumussuyu G. A quality analysis of disc herniation videos on YouTube. *World Neurosurg*. 2019;124:e799-e804. [CrossRef]
9. ReFaey K, Tripathi S, Yoon JW, et al. The reliability of YouTube videos in patients education for glioblastoma treatment. *J Clin Neurosci*. 2018;55:1-4. [CrossRef]
10. Ovenden CD, Brooks FM. Anterior cervical discectomy and fusion YouTube videos as a source of patient education. *Asian Spine J*. 2018;12(6):987-991. [CrossRef]
11. Hesse BW, Moser RP, Rutten LJ. Surveys of physicians and electronic health information. *N Engl J Med*. 2010;362(9):859-860. [CrossRef]
12. The daily, Monday, May 10, 2010. *Canadian Internet Use Survey [Internet]*. [cited 2020 May 17]. Available from: https://www150.statcan.gc.ca/n1/daily-quotidien/100510/dq100510a-eng.htm.
13. Alotaibi NM, Samuel N, Wang J, et al. The use of social media communications in brain aneurysms and subarachnoid hemorrhage:

a mixed-method analysis. *World Neurosurg*. 2017;98:456-462. [CrossRef]
14. Heo J, Chun M, Lee HW, Woo JH. Social media use for cancer education at a community-based cancer center in South Korea. *J Cancer Educ*. 2018;33(4):769-773. [CrossRef]
15. Tolu S, Yurdakul OV, Basaran B, Rezvani A. English-language videos on YouTube as a source of information on self-administer subcutaneous anti-tumour necrosis factor agent injections. *Rheumatol Int*. 2018;38(7):1285-1292. [CrossRef]
16. Samuel N, Alotaibi NM, Lozano AM. YouTube as a source of information on neurosurgery. *World Neurosurg*. 2017;105:394-398. [CrossRef]
17. Brooks FM, Lawrence H, Jones A, McCarthy MJH. YouTube™ as a source of patient information for lumbar discectomy. *Ann R Coll Surg Engl*. 2014;96(2):144-146. [CrossRef]
18. Singh AG, Singh S, Singh PP. 2012. YouTube for information on rheumatoid arthritis—a wakeup call. *J Rheumatol*. 2012;39(5):899-903.
19. Staunton PF, Baker JF, Green J, Devitt A. Online curves: a quality analysis of scoliosis videos on YouTube. *Spine*. 2015;40(23):1857-1861. [CrossRef]
20. Fox S. *Most Internet Users Start at a Search Engine When Looking for Health Information Online. Very Few Check the Source and Date of the Information They Find*. PEW/Internet and American Life Project; 2006.
21. Desai T, Shariff A, Dhingra V, Minhas D, Eure M, Kats M. Is content really king? An objective analysis of the public's response to medical videos on YouTube. *PLoS ONE*. 2013;8(12):3-5. [CrossRef]
22. Tartaglione JP, Rosenbaum AJ, Abousayed M, Hushmendy SF, DiPreta JA. Evaluating the quality, accuracy, and readability of online resources pertaining to hallux valgus. *Foot Ankle Spec*. 2016;9(1):17-23. [CrossRef]
23. Erdem MN, Karaca S. Evaluating the accuracy and quality of the information in kyphosis videos shared on YouTube. *Spine*. 2018;43(22):E1334-E1339. [CrossRef]
24. Morahan-Martin JM. How internet users find, evaluate, and use online health information: a cross-cultural review. *Cyberpsychol Behav*. 2004;7(5):497-510. [CrossRef]
25. Winker MA, Flanagin A, Chi-Lum B, et al. Guidelines for medical and health information sites on the internet: principles governing AMA web sites. American Medical Association. *JAMA*. 2000;283(12):1600-1606. [CrossRef]